Melissa K Hofman. Moving Towards a Social-Health Information Exchange: Analyzing the Health IT Systems Necessary for Holistic Healthcare. A Master's Paper for the M.S. in I.S degree. July, 2018. 62 pages. Advisor: Amelia Gibson

Health information technology has the potential to transform the healthcare industry with a robust health information exchange. This paper examines what data is to be recorded and shared, with whom is the data to be shared, who is to have access to the data, who gets to decide all of this? Recent studies suggest that the recent deluge of big data require interdisciplinary efforts moving forward. Analysis of semi-structured interviews with a variety of stakeholders throughout the industry revealed frustration with the current systems and optimism about the future. Results revealed that all parties are willing and eager to be a part of the growing conversation, though the majority do not feel included. All participants favorably discussed the potential for health IT to positively influence healthcare if certain considerations are taken into account. Primary barriers to implementation, privacy, financial, data collection, and stakeholder buy-in, were consistent with previous research.

Headings:

Health Information Exchange

Holistic Health

Health IT

Big Data

TOWARDS A MORE HOLISTIC HEALTH INFORMATION EXCHANGE

by
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INTRODUCTION

Healthcare is on the brink of a paradigm shift—or at least it has the potential to be. Advances in technology have generated a vast amount of individual and population data and a variety of methods to exchange them, but practices have not adapted as quickly as the technology. The healthcare system initially began employing advances in health information technology (health IT) primarily to expedite administrative tasks and insurance filings, thus the systems were built with those in mind and able to manage data rather than information (Hoyt & Bernstam, 2014; Adler-Milstein, Embi, Middleton, Sarkar, & Smith, 2017). The trend towards increased use of health IT calls for efforts to leverage health data as information, thus systems must be designed and restructured to allow for integration and exchange at the intersection of medical, public health, and social work fields, actors and stakeholders that were once considered disparate. This idea of silos within the healthcare system and beyond served a purpose, but has begun to limit progression and will ultimately grossly hinder the potential of health informatics' benefits to individuals and society at large (Vest & Gamm, 2010; Kuperman, 2011; Mori, Mazzeo, Mecurio, & Verbicaro, 2012; Adler-Milstein et al., 2017). Researchers and academics are making strides within the fields of social work, health informatics, public health, and medicine, but unless these advances are integrated with those amongst other fields, we risk falling short of capitalizing on discoveries have universal impact. This all comes down to simple research questions—what data is to be recorded, what data is to be

shared, with whom is the data to be shared, who is to have access to the data, who gets to decide all of this—that become inordinately complex when dealing with the healthcare system. Upon answering these questions, a significant barrier to health information exchange (HIE) remains—how are the data able to be shared and understood across various groups and what does that mean for healthcare—essentially, how do we ensure health information systems (HIS) can generate information from data and in turn knowledge and wisdom (Hoyt & Bernstam, 2014). Adler-Milstein et al. (2017) suggest that we are experiencing a "chasm between the current health IT ecosystem and the health IT ecosystem that is desperately needed" (p. 1036). Conversations with the various stakeholders will answer additional research questions: what is the gap between the current state of health IT and its potential? What are the benefits of integrating data from various systems and the Internet of Things (IoT) into electronic health records? And ascertain what behavioral, ethical, logistical considerations must be taken into account in order to achieve maximum utility of this cross-sectional information exchange?

1.1 HEALTH INFORMATION EXCHANGE

Computers and health IT have transformed our traditional systems of healthcare, digitizing health information as data to be stored, process, and shared (Brown, Pasupathy, & Patrick, 2013). As health IT progressed, the potential uses of these data gathered from electronic health records extend far beyond administrative tasks, which were the initial focus (Kuperman, 2011, Brown et al., 2013). Health IT was originally seen as a tool for automation rather than transformation (2013). The driving forces behind health IT were improving healthcare efficiency and quality, reduction of costs, better communication and coordination, as well as continuity of care (Hoyt & Bernstam, 2014). Early HIE

models recognized the need for electronic health data to be exchanged within systems, enabling the opportunity for the potential to be realized (2014). Health IT strategies continued to evolve incrementally, with no cohesive commitment until government initiatives such as the HITECH Act and Meaningful Use eventually incentivized and required certain levels of interoperability, but these minimum requirements allowed for variation in the implementation and usage of EHRs (Kuperman, 2011). Efforts attempting to expand HIEs from single-institution systems to regional and national are underway, and while integration is increasing, it is not widespread (The Office of the National Coordinator for Health Information Technology [ONC], 2017) and many barriers and concerns remain. The deluge of data arriving from traditional—clinical records, lab results—and non-traditional—patient-generated data via the IoT, social services—as we become a data-driven society will introduce vast potential as well as new risks (Edwards, Hollin, Barry, & Kachnowski, 2010; Adler-Milstein et al., 2017). As we shift towards integrating our health IT via a cohesive, robust HIE system, recent implementation and interoperability lessons can be explored in order to resolve current issues and mitigate both foreseen and unforeseen future ones (Vest & Gamm, 2010). The nature of healthcare demands a timeliness and accuracy of information shared from various HIS, and such demands and complexity impede seamless interoperability (Edwards et al., 2010; Aziz, 2017). The prospective benefits, however, provide collective incentive to improve HIE and HIS technologies (ONC, 2017).

Current barriers to HIE interoperability are seen at the technology, political, operational, financial and cultural levels. This current situation stems from the origin of HIE where high costs, conflicting stakeholder agendas, vendor-driven projects, and inadequate

technology shaped the environment in which the systems were created (Brown et al., 2013; ONC, 2017). Edwards et al. (2010) discussed the role that unique "digital languages" among the various stakeholders as both a barrier to HIE and an incentive to focus on interoperability measures (2010, p. 23). Bernstam et al. (2014) also emphasized these semantic gaps, underscoring the idea that data from one system may not seamlessly translate in meaning to a different agent, regardless of the technical ability of the systems to transfer data. Privacy and security, various economic concerns, stakeholder buy-in and healthcare policy are widely cited as major barriers (Brown et al., 2013; Aziz, 2017; ONC, 2017).

1.2 HOLISTIC CARE

Clinical, community, and public health professionals have access to data from individuals and populations at large. The current systems, however, do not allow them to capitalize on the data from each other (Vest & Gamm, 2010; Kuperman, 2011; Adler-Milstein et al., 2017). Discussions regarding interoperability are primarily concerned with the exchange of data along a more linear path—sharing information with doctors within a region or hospital, filling prescriptions. Even this level of interoperability has proven to be difficult to achieve due to health language, knowledge, policy, and technical barriers (Brown et al., 2013; Aziz, 2017; ONC, 2017), leading the focus to remain on areas of Meaningful Use, standardization and security. We can learn from this as we move forward towards further integration of data, with foresight of what data we could be utilizing differently, if we had a certain degree of standardization and common language (Adler-Milstein et al., 2017).

However, as Bernstam et al. (2014) discuss, health IT alone cannot solve our healthcare woes. As technology advances, many of the technical barriers are alleviated over time, exposing underlying cracks within our healthcare system. Recently, scholars have been drawing attention to the growing gap between healthcare and social services, and the potential for health IT to bridge that gap (Nguyen, Chan, Makam, Stieglitz, & Amarasingham, 2014). There is an emerging sentiment that social and environmental factors play a significant role in an individual's health, leading to the promotion of a holistic healthcare system in which social needs are addressed and self-care is encouraged (2014). Mori et al. (2012) introduce the idea that we ought to be concerned with co-operability amongst agents and not solely on the interoperability of systems. This approach falls in line with accountable care organizations (ACOs) that accentuate a collaborative effort between institutions, clinicians, and patients (Brown et al., 2013; Aziz, 2017). This intersection of data and information will lead to vast knowledge needed to paint a broader picture of health at an individual and societal level. Many scholars have called for interdisciplinary teams to be involved in the design, policy frameworks, and to collaborate in the uses of HIE (Kharrazi, Lasser, Yasnoff, Loonsk, Advani, Lehmann, ... & Weiner, 2016; Adler-Milstein et al., 2017). Collaborative efforts to acknowledge the intersection of health and social care ensure a shared vision moving forward in healthcare (Rigby, Hill, Koch, Keeling, 2014). Rigby et al. (2014) emphasize that health requires much more than medicine to maintain an optimal level of wellness, and that social care is needed to support health. Scholars argue that many discussions of this intersection and the need to acknowledge it are superficial in nature without tangible action taking place

(2014; Adler-Milstein et al., 2017). This research aims to deviate from the vague discussions and instead incite action to move forward.

Consider a patient in the hospital, who may be a part of a very specific population that epidemiologists have critical insight into, but the EHR information being limited to the individual patient's data; this information will be missed and effectively useless. If we discover and analyze the potential intersections of data and their benefits, we will be able to be more proactive in creating standards and mappings for data and information.

The evolution of the IoT provides further incentive to explore these cross sections and ensure seamless interoperability, as more and more data becomes available for utilization. While IoT devices raise new concerns, their rapid adoption cannot be ignored. Integrating information technologies is a necessity (Aziz, 2017), and doing so mindfully will allow us to reshape approaches to overall health. This integration will not be without disruption and resistance and will need to be proven to have significant value to the health care system, particularly in regards to patients. Conversations can shed light not only on what is going wrong with health IT, but what is the ultimate goal with health IT and how can HIE help us reach that goal?

Bernstam et al. (2014) emphasized the importance of collaboration amongst the various stakeholders moving forward with health IT initiatives. In the study, interviews with clinicians, public health professionals, social workers, health informaticians, and wellness professionals will provide insight into the intricacies and variability of health data. This insight will provide potential uses and valuable intersections of the data, allowing for further justification of the benefits of pursuing research of cross-sectional HIE. Upon sufficient justification, the foreseen barriers to implementation and seamless

interoperability will be outlined and addressed with suggestions for proactive mitigation. Understanding the various languages and perspectives and having a sense of how each party acts and thinks will allow systems to be created to account for barriers and accommodate them. Beyond the behavioral considerations of various groups, the ethical questions regarding privacy and security will be addressed as well. Instead of skirting complex and sensitive topics, the research will attempt to work with, rather than against, them, accepting certain impediments as inevitable. Explicitly outlining the barriers will allow them to be analyzed with recommendations for overcoming them with the input gathered from the various parties.

LITERATURE REVIEW

2.1 INTRODUCTION

The past twenty years has seen a resurgence in research in the medical and healthcare fields, as innovations and advances in information technologies began to transform the landscape, particularly in regards the vast amounts of data being collected from various sources. The rapid evolution of health IT, formative nature of electronic health records (EHRs) and HIE, and growing prominence of big data creates a dynamic of limited research and emphasis on the potential of their impacts rather than evidence of it. Available literature will thus be reviewed in order to identify themes and be more concrete about their implications.

Given the nature of the research questions, this paper will examine various topics through a healthcare lens. The literature review will present a broad overview of the evolution of health IT, current state of HIE, challenges with seamless exchange and barriers to implementation, with particular emphasis on stakeholder buy-in, to gather a sense of their past and future trajectory. It will also examine big data as a phenomenon what it could mean for healthcare. Research regarding holistic care and social approaches to health and wellness will be analyzed to better understand these approaches and what further challenges and opportunities they create for health IT and patient-centered healthcare. Finally, general sentiment regarding what considerations must be taken into account moving forward will be analyzed.

2.2 GENERAL LANDSCAPE OF THE RESEARCH AREA

The digitization of medical records in the form of electronic medical records (EMRs) and EHRs initialized the health IT revolution and early sentiment believed that this alone would transform healthcare (Murdoch & Detsky, 2013). Health IT was driven by financial incentives, primarily by insurance companies, and facilitated office communication and clerical work. Under this motivation, health IT was seen as a means to automation rather than a vehicle for true transformation (Brown et al., 2013). Once data began populating EHRs, however, researchers took note and speculation began about the potential uses for this data and how it could be exchanged and accessed. The data generated, which was once seen as a byproduct of automation, quickly became the very thing that could revolutionize healthcare (Murdoch & Detsky, 2013). Scholars began citing data sharing and information brokerage as the critical piece in advancing healthcare (Brown et al., 2013; Elliot, Holmes, Davidson, La Chance, Nelson, & Steiner, 2013; Hoyt & Bernstam 2014). It was quickly realized that data itself was unable to live up to the hype, and scholars discussed that the systems that had been created were "data rich but information poor" (Hoyt & Bernstam, 2014, p. 21). HIE and interoperability efforts became a primary focus of researchers, as it was becoming increasingly apparent that the health IT revolution was falling short of its potential due to a number of growing barriers stemming from disparate motivations behind the usages of EHRs and their data (Damschroder, Aron, Keith, Kirsh, Alexander, & Lowery, 2009; Edwards et al., 2010; Vest & Gamm, 2010; Kuperman, 2011; Bernstam et al., 2014 Brown et al., 2013; Hoyt & Bernstam, 2014; Manojlovich, Adler-Milstein, Harrod, Sales, Hofer, Saint, & Krein, 2015; Adler-Milstein et al., 2017).

We have become a more digitized and mobile society and generate data every day, leading scholars to address the broad themes of big data, especially the prospective utilization of the data and the inevitable complications that will arise (Adler-Milstein et al., 2017; Tiase, 2017). Many encourage proceeding with caution, as the literature exposes the likelihood of failure if certain challenges are not met with cohesive efforts (Murdoch & Detsky, 2013; Salas-Vega, Haimann, & Mossialos, 2015). This analysis will provide context for the framing of the interview questions. The rapid evolution of health IT presents some difficulty with remaining up-to-date on its happenings and create gaps between literature, research and practice.

2.3 HEALTH INFORMATION EXCHANGE & INTEROPERABILITY

As health IT evolves, so does the terminology and concepts framing HIT research. For the purposes of this paper, HIE will be used conceptually, rather than an organization or system, to represent the electronic exchange of health data and information between these systems and organizations in a way that maintains the meaning of the information (Kuperman, 2011; Brown et al., 2013; Almoaber & Amyot, 2017; HIMSS). When the initial focus of EHRs and HIE was to ensure the transfer of medications, allergies, lab results, and administrative data (Kuperman, 2011), with the goal of efficient, safe, cost-effective care (Hoyt & Bernstam, 2014; HIMSS). Beyond these benefits, HIE was believed to be the catalyst for improved patient care and satisfaction (Almoaber & Amyot, 2017) as well as the anecdote to the issue of fragmented personal health information (Vest & Gamm, 2010; Almoaber & Amyot, 2017). As data being collected moved into clinical data warehouses, shared databases that house clinical data from EHRs and other various sources (Bernstam, Johnson, & Cohen, 2014), the benefits of

HIE beyond the scope of patient care began to be discussed, such as quality improvement in clinical practices and public health research (HIMSS). The range of pursuits, from care encounters to epidemiological research, require a networked, interoperable health system that has yet to be realized (Edwards et al., 2010; Adler-Milstein et al., 2017). While the HITECH Act and meaningful use initiatives gave way to numerous HIE interoperability efforts and though improvements have been made (Kuperman, 2011; Salas-Vega et al., 2015), means of exchange remain underutilized and inefficient (Lehmann, Kressly, Hart, Johnson, & Frisse, 2017), resulting in a collection of disparate systems that are not designed to capitalize on health IT and instead may end up creating more problems than they solve (Edwards et al., 2010; Manojlovich et al., 2015; Adler-Milstein et al., 2017). Lehmann et al. (2017) suggested HIE was an empty promise, a sentiment prevalent within recent literature, as scholars acknowledge the complexity and fragmentation of health information systems (Edwards et al., 2010; Vest & Gamm, 2010; Salas-Vega et al., 2015; Adler-Milstein et al., 2017; Almoaber & Amyot, 2017). While literature on interoperability and HIE are limited (Edwards et al., 2010; Almoaber & Amyout, 2017), scholars agree that HIE has the potential to shift healthcare on many levels, from individual to national, (Brown et al., 2013), if certain behavioral, logistical, ethical and technical concerns are addressed and overcome (Vest & Gamm, 2010; Kuperman, 2011; Brown et al., 2013; Bernstam et al., 2014; Salas-Vega et al., 2015; Adler-Milstein et al., 2017). Researchers are currently grappling with discerning what interoperable measures will actually improve the quality of care (Kuperman, 2011) and what breadth of interoperability to hope to achieve (Salas-Vega et al., 2015). Fortunately, as interoperability has been increasingly discussed as essential to getting the “right

information, to the right person, at the right time" (Almoaber & Amyot, 2017, p. 44), researchers have been addressing the need to better understand interoperability and the barriers to it (Edwards et al., 2010; Salas-Vega et al., 2015) in order to design systems with it in mind (Edwards et al, 2010) to move beyond the legacy siloed EHRs of early health IT (Vest & Gamm, 2010; Kuperman, 2011; Adler-Milstein et al., 2017). Much of the literature emphasizes the importance of the right person getting the right data and thus extracting the right information, there is a lack of declarative statements from clinicians, social workers, public health researchers and other professionals as far as what they need, why they need it, and how to obtain and disseminate it with ease. The majority of the literature is suggestive and more definitive steps for action need to be addressed.

2.4 BARRIERS TO IMPLEMENTION

Barriers to implementation and interoperability have been a primary focus of researchers as the barriers impede adoption and buy-in of health IT. Existing literature suggests that while health IT has achieved some of its goals, more is going wrong, with failures outnumbering successes (Salas-Vega et al., 2015; Almoaber & Amyot, 2017). Lehmann et al. (2017) found the current state of HIE within organizations to be either low implementation, little intention to implement, or a lack of support for the aspired implementation. It is important to analyze the barriers at every stage of the process in order to move towards interoperability amongst a greater number and more disparate systems. Without addressing the lack of cohesion within similar systems, expanding the scope does not bode well for success. Many researchers noted that technology was advancing more rapidly than clinicians were able to assimilate to new practices (Hoyt & Bernstam, 2014) and faster than researchers could keep up with (Elliot et al., 2013).

Sparse literature in certain domains creates a dynamic where health IT is being integrated into practice by healthcare professionals without research to suggest what is effective. Ultimately, this leads to clinicians, patients, and researchers to become hesitant to employ health IT, grossly underutilizing it.

Almoaber & Amyot (2017) performed a systematic review and found four main categories of barriers—privacy and security, finance and sustainability, participation of stakeholders, and technical and organizational, supporting Edwards et al.'s (2010) findings that standards, security concerns, competition and money, and federated systems were the primary barriers to seamless HIE. The consistency of barriers and concerns have resulted in a stagnant state of health IT adoption, with these needing to be figured out in order to move forward.

2.4.1 Technical & Organizational

Technical barriers are widely discussed within the literature, most notably a lack of standardization and interoperability (Kuperman, 2011; Bernstam et al., 2014; Adler-Milstein et al., 2017). These semantic gaps between data and information, ambiguous definitions (Bernstam et al., 2014) and unique digital languages of each stakeholder (Edwards et al., 2010) prevent unified, standard terminologies (Brown et al., 2013). This ultimately leads to clinical resistance (Brown et al., 2013), the potential for meaning to get lost in translation, imperfect information (Bernstam et al., 2014), communication and treatment errors (Manojlovich et al., 2015) and general lack of adoption (Salas-Vega et al., 2015; Almoaber & Amyot, 2017). Health IT has exposed the clear variations in care and practices (Hoyt & Bernstam, 2014), and these need to be addressed by the technology system or healthcare in general. The variety of forms in which health data can take

presents further challenges (Edwards et al., 2010), though advances in technology, such as machine learning and natural language processing, have made the task of handling unstructured data in clinical notes less insurmountable (Murdoch & Detsky, 2013). Scholars suggest that the lack of interoperability stem from the initial development being absent efforts of explicit standards and protocols, impeding data retrieval (Adler-Milstein et al., 2017), and others have found that the inherent heterogeneity of the systems accessing health data require a fundamental base of interoperability (Edwards et al., 2010). Furthermore, interoperability efforts that have been put in place are often flexible, allowing organizations to meet certification requirements without being truly interoperable with other systems (Kuperman, 2011). Scholars are calling for research into common data elements and sets (Salas-Vega et al., 2015; Adler-Milstein et al., 2017) to address interoperability issues, but there is has yet to be an agreement as to who should be funding and leading these efforts (Kuperman, 2011).

Additionally, new technologies required advanced training and raise usability concerns to consider during design and integration (Hoyt & Bernstam, 2014). Despite the technical barriers, scholars stress that technology alone cannot solve healthcare problems and does not create them (Vest & Gamm, 2010; Bernstam et al., 2014) and that barriers may arise at various levels (Damschroder et al., 2009). Adler-Milstein et al. (2017) propose that our barriers now are those of execution rather than knowledge, corroborating Bernstam et al.'s (2014) suggestion that is not just about what system is being implemented, and is now about how and in what context it is implemented. We have a sense of what needs to be done, but we have yet to figure out how to best do it, and what role each player should take (Adler-Milstein et al., 2017). As mentioned, technology is outpacing research and

practice, and while further research needs to be done to continue to ameliorate technological barriers, the lessons we have learned ought be utilized to foresee barriers that will arise as more data from more sources becomes available. Further support is needed beyond addressing technical challenges, however (Vest & Gamm, 2010).

2.4.2 Privacy & Security

Healthcare information has a unique sensitivity (Manojlovich et al., 2015) and thus requires a particular focus on privacy and security that may not be as important or complex within non-healthcare data warehouses (Elliot et al., 2013). Privacy and security issues were unsurprisingly widely cited as a barrier to implementation of HIE (Brown et al., 2013; Murdoch & Detsky, 2013; Adler-Milstein et al., 2017). There are few safeguards to ensure safety (2017) and no frameworks to guarantee privacy (Kuperman, 2011). Edwards et al. (2010) emphasize the interplay of ethics, law, policy and patient protection within health data security. A breach in a health information system could lead to medical errors, results in denied coverage or denial of employment (2010). Identity theft, unauthorized access and misuse of data were cited as other concerns (Almoaber & Amyot, 2017). Considerations at the patient level have also been discussed, regarding stigma and embarrassment of certain symptoms and issues (Edwards et al., 2010). Governmental agencies are encouraged be proactive in privacy efforts, assuring a basic level of privacy and mitigating data inaccuracy risks (Adler-Milstein et al., 2017). Elliot et al. (2013) discuss necessary compliance with government regulations and organizational policies as further constraints on health information systems.

2.4.3 Financial

Almoaber & Amyot (2017) suggest that the current system lacks a sustainable business model, upholding Vest & Gamm's (2010) conclusion that long-term financial uncertainty could spoil the most advanced technology efforts. High start-up and ongoing costs, ambiguity regarding who should incur the costs, and questions surrounding tangible return on investment have been discussed (Vest & Gamm, 2010; Hoyt & Bernstam, 2014).

2.4.4 Buy-In Amongst Stakeholders

In their overview of managing change, Lorenzi & Riley (2000) discuss the fundamental necessity that all stakeholders acknowledge and believe in the need for change. Damschroder et al. (2009) found that the quality and validity of the evidence supporting the anticipated outcomes were influential on stakeholder perceptions of change. The scholars discussed perceived difficulty of rollouts, including scope, timeframe, and complexity. HIE and EHR efforts have made national headlines for their fairly deleterious rollouts (Monegain, 2013; Herman, 2014; Davis, 2016).

Lack of stakeholder buy-in has been widely cited as an impediment to health IT adoption from all aspects of healthcare, from clinicians (Damschroder et al., 2009), patients (Adler-Milstein et al., 2017) and societal (Vest & Gamm, 2010). Almoaber & Amyot call for efforts to "educate and engage relevant stakeholders" (2017, p. 57) in order to address the recurrent barrier of lack of buy-in. Vest & Gamm (2010) warned that without universal buy-in, we risk creating a cycle of repositories replete with incomplete, isolated, underutilized data. Transitioning from paper-based records to electronic records has created growing pains within the industry, as it requires alterations of processes, workflow and behavior within healthcare organizations (Brown et al., 2013). Health IT

requires a systems change, and with that will bring about resistance. Such a "disruption" (2013, p. 11) will be welcomed only if all stakeholders believe in the value-added.

In order to increase and encourage buy-in, all stakeholders must be considered and invited to participate in the conversation about health IT and the exchange of health information. Upon acceptance upon all agents that the change is necessary, they must also believe they are capable of seeing it through. Damschroder et al. (2009) cite self-efficacy as a critical player in accepting change. In anticipation of the way health care changes, we must incorporate continual education (Hoyt & Bernstam, 2014) of all involved parties—from practitioners to patients.

Lehmann et al. (2017) suggest that success of HIE will be determined by the incentives found on both the sending and receiving ends of health information. Murdoch & Detsky (2013) raise the question as to whether or not an absence of clinical experience amongst many big data advocates, which tend to be researchers, public health organizations, and companies, created a rift between what is purported and what is necessary and feasible. Given that stakeholders, including clinicians who maintain little incentive to buy in (2013), turn to guidelines, published articles, peers and pilot programs (Damschroder et al., 2009), research into feedback from clinicians and health care professionals regarding HIE could be proven to be influential into getting more people from all sides on board. Further, acknowledging these aforementioned barriers to the primary users of the system may provide insight into ways to mitigate the concerns and prioritize which ones to address moving forward.

2.5 BIG DATA & THE INTERNET OF THINGS

The maturation of health IT and rapid advancement of technologies has given way to the "transition of data from refuse to riches" (Murdoch & Detsky, 2013, p. 1351). Data is no longer generated and forgotten in archives. While the data stored via EHRs was multiplying rapidly, an increasing number of smart technologies were being introduced, leading way to the IoT (MapR, 2016). The convergence of these smart, interconnected devices with the shift towards digital health gives way to a deluge of health data. Health IoT—e-health (electronic health), m-health (mobile health), vast amounts of diverse data types, genomics, and bioinformatics (Salas-Vega et al., 2015) is projected to reach $120 billon in the next few years (MapR, 2016). While literature suggest that various areas of medicine—mental and public health, cardiology, oncology, and neurology— are benefiting from this growth (Salas-Vega et al., 2015), health care professionals are already overwhelmed by the current volume of data (Tiase, 2017) and are without sufficient tools to support the exchange of all of the disparate data.

With the rapid and ubiquitous rise in wearable devices and mobile applications (Qi, Yang, Min, Amft, Dong, & Xu, 2017), the big data deluge is inevitable (Tiase, 2017) and will have an immense impact on the healthcare system. The novel nature of big data and the digitized society give it an exoticism and uncertainty which leads scholars, health care professionals, and the general public to speak of it in ambiguous and vague terms. Discussions surrounding big data and health IoT regard the potential and advantages. Scholars highlight the possibility that big data could facilitate patient-focused healthcare, which has remained elusive thus far, ultimately lowering costs and improving care (Salas-Vega et al., 2015; MapR, 2016; Qi et al., 2016). Patient-generated health data

(PGHD) provides valuable information that is often unavailable elsewhere (Tiase, 2017). PGHD has the potential to alleviate documentation burdens on clinicians (2017), reduce patient visits (MapR, 2016), drug safety and efficacy (Salas-Vega et al., 2015), increase self-empowerment and improve clinical decision making (Qi et al., 2017). Murdoch & Detsky (2013) warn that big data, EHRs, and health IT are not foolproof, a sentiment echoed by many scholars who discuss the anticipated legal and financial risks of the IoT and its data (Salas-Vega et al., 2015; Qi et al., 2017).

Data security and confidentiality are primary focuses of current research (Salas-Vega et al., 2015; Adler-Milstein et al., 2017), as declarative initiatives for governance, management, and sustainability of systems integrating this data do not exist yet. Qi et al. (2017) suggest that traditional healthcare systems are outdated and that PGHD signals a shift towards personalized health systems. Others are less certain about the actual impacts of PGHD (Adler-Milstein et al., 2017), but scholars agree that if standards can established and met, EHR systems will need to be able to readily accept this data and incorporate it into health IT.

The rapid innovation of technology renders some of the discussion about big data obsolete; new advances appears with each new season and others fade away with each new craze. Fielding opinions from healthcare providers and information professionals will provide a better sense of the current sentiments regarding big data and patient-generated health data.

2.6 HOLISTIC CARE & SOCIAL-HEALTH INFORMATION EXCHANGE

Current literature calls for further discussion on the shift towards a health-social intersection of healthcare. While healthcare providers are generally in favor of the move

and agree on its importance, the current landscape lacks legitimate discussion as far as tangible steps towards implementation and sustainability (Nguyen et al., 2014). The World Health Organization defines health as a "state of physical, mental and social well-being" (Rigby et al., 2011). Rigby et al. (2011) suggest that while health informatics is expanding and improving healthcare delivery, social care informatics support has yet to be established.

2.6.1 Social-Health Information Exchange & Social Determinants of Health

Social-health information exchange (S-HIE) can leverage health IT to bridge the gap between social care services and healthcare, enabling communication and coordination amongst various sectors (2011; Nguyen et al., 2014).

S-HIE provides a backbone by which healthcare can shift towards alternative care methods, such as accountable care organizations and patient-centered care (Brown et al., 2013), ultimately leading to improved community health (Nguyen et al., 2014).

Vest & Gamm (2010) investigate the need for innovative approaches to tackling chronic illnesses and the redefinition of roles of non-physician healthcare professionals amidst the shift towards holistic care. Social determinants of health (SDH), environmental factors affecting health, functioning and quality-of-life outcomes and risks, have been gaining traction in research, as scholars emphasize the importance of integrating social determinants into healthcare practices (Rigby et al., 2011; Nguyen et al, 2014; Tiase, 2017; LaForge, Gold, Cottrell, Bunch, Proser, Hollombe, …& Clark, 2018). LaForge et al. (2018) discuss the lack of defined roles and methods for addressing social needs in primary care settings and acknowledge national initiatives to integrate SDH data into EHRs. SDH screening is believed to expose "upstream" factors related to health

problems, inform clinical decision making, and identify necessary community resources for patients (2018). Nyugen et al., 2014 discuss the link between unmet social needs, such as food insecurity, unemployment and unstable housing, and the excessive use of healthcare resources. Incentives for addressing this upstream issues are boundless, ultimately leading to lower healthcare costs and general well-being for members of society.

Social service and healthcare providers were found to be enthusiastic about the potential for S-HIE to align care efforts and facilitate care coordination (Nguyen et al., 2014). Literature supports the notion that care coordination and shared resources between the community providers and clinicians are pivotal in addressing social needs and encouraging self-care and prevention (2014). Poulymenopoulou, Malamateniou, & Vassilacopoulos (2013) emphasize that realizing the vast benefits of holistic care requires collaboration amongst participating organizations, bridging the current gap between health and social services. Social service leaders believe that S-HIE will demonstrate the links between social service provisions and longitudinal positive health outcomes (Nguyen et al., 2014).

2.6.2 Barriers to S-HIE

Though the need for S-HIE has become more evident (LaForge et al., 2018), existing barriers remain and new barriers arise. Scholars suggest that regardless of the potential of S-HIE, unless these are addressed and the risks mitigated, the systems will not be utilized (Nguyen et al., 2014; Witham, Frost, McMurdo, Donnan, & McGilchrist, 2015). Primary concerns on the clinical side were financial, technological, and security (Haluza & Jungwirth, 2018) and increased logistical and documentation burden (LaForge et al.,

2018). There is also a lack of clarity as to which data matters most to the various stakeholders (2018), thus conversations with them would provide insight as to what information they want available via S-HIE and what costs they are willing to incur to make it available to them. Stakeholder buy-in is critical to moving forward with S-HIE. Haluza & Jungwirth's (2018) findings that low doctor acceptance of these initiatives were impeding adoption contrast other studies that found a more positive attitude towards them (Rigby et al, 2011; Witham et al., 2015). Rigby et al. (2011) identify the main challenges to S-HIE as disparate information needs of each stakeholder, lack of standardization and policies, context-specific knowledge, and lack of citizen empowerment. These interoperability challenges give way to redundancy and inefficiency (Nguyen et al., 2014). Furthermore, the nature of social services and particular sensitivity of social and mental health information raise unique concerns with S-HIE. Deciding what data ought to be shared and how to adequately train providers and volunteers to ensure informed consent and appropriate use of the data help mitigate security and privacy risks (2014). Certain data sets are also functionally inaccessible, such as jail records and homeless outreach programs (Nguyen et al., 2014) and maximum utility of S-HIE requires all relevant data sets be able to be linked (Witham et al., 2015).

2.6.3 Big Data

Our information-based society and the growing usage of wearable devices and mobile applications provide an opportunity for massive amounts of data to be collected and shared effectively and efficiently (Haluza & Jungwirth, 2018). These technologies are revolutionizing healthcare and social services, providing patients the opportunity to link traditional health data with their personal, social, and environmental data through their

own input without exhaustive and intrusive interviews (Murdoch & Detsky, 2013). LaForge et al. (2018) call upon researchers to investigate leveraging these technologies to collect and integrate SDH data.

2.6.4 Moving Forward

Literature suggests a need to address how to implement holistic approaches and how to use SDH once collected (Witham et al., 2015; LaForge et al., 2018). Scholars emphasize the importance of gathering opinions and expectations regarding S-HIE and holistic healthcare from the various stakeholders in order to move forward with this integration, as organizational, cultural, and contextual matters are at play (Poulymenopoulou et al., 2013; Nguyen et al., 2014; Witham et al., 2015; Haluza & Jungwirth, 2018). Regardless of whether scholars are acknowledging holistic healthcare approaches in a direct way or only alluding to their importance, it is clear that a shift is being considered and arguably promoted. Gathering sentiments from various members of the healthcare field and general public that will ultimately be responsible for supplying and utilizing the data from different health information systems will help ensure that the proper data is being shared and accessed by those who can maximize their utility and in the most effective and efficient way.

2.7 PATIENTS

The idea of patient-centered healthcare has gotten lost amidst the health IT wave and financial incentives for expediting billing and administrative tasks, thrusting insurers to the forefront. Recent literature, however, highlights the potential for health IT to redirect the focus back to patients and ultimately empowers them to be their own biggest healthcare advocate (Murdoch & Detsky, 2013). A consensus reached in the 2011 AMIA

Policy Invitational was that health IT's main purpose was to support patient care and improved outcomes (Adler-Milstein et al., 2017). However, research shows that we have yet to discover how to leverage health IT to solve complex problems or improve functionality (Manojlovich et al., 2015). There is a glaring omission of patient participation in the research (Kharrazi et al., 2016; Adler-Milstein et al., 2017), leading to assumptions about what data patients want and need for health and wellness (2017). Without including patients in the conversation, they are unable to see the value in how S-HIE could improve their care (Almoaber & Amyot, 2017). Security and trust concerns dominate the hesitancy to share information, but LaForge et al. (2018) found that patients were actually willing to share their SDH data. PGHD and m-health encourage patient engagement and autonomy (Murdoch & Detsky, 2013; Adler-Milstein et al., 2017; Tiase, 2017), but standardization for this data is generally non-existent (Adler-Milstein et al., 2017). Poulymenopoulou et al. (2013) suggest that sociotechnical and holistic healthcare approaches serves patients the best. A collaborative effort is needed to begin to work towards this shift.

2.8 NEXT STEPS

The conjunction of Health IT, big data, and holistic healthcare signal significant shifts in the healthcare industry, and scholars are calling for proactive, rather than the industry-standard reactive, measures as we move forward (Adler-Milstein et. al, 2017). PGHD enables the collection of data anywhere at any time, creating a more complete picture of a patient's health than previously possible (Tiase, 2017). Scholars emphasize the need for collaboration and cooperation amongst caregivers and patients in order to reach a consensus on what data to collect, integrate, and share (Mori et al., 2012; Kharrazi et al.,

2016; Tiase, 2017) and who should be responsible for leading and implementing these initiatives and standards (Edwards et al., 2010), thus encouraging in-depth interviews with these various agents to garner a concrete sense of where they stand.

METHODS

3.1 INTRODUCTION

The interdisciplinary nature of the research questions requires input from various stakeholders and groups. The current literature regarding HIE is primarily concerned with the exchange of health information between doctors within the same building to exchange laboratory results, medications, allergies and test results or within the same network in order to follow the patient's visits (Kuperman, 2011). EHRs and health information systems were designed to serve administrative tasks and billing and insurance needs. As technology progressed, however, the vast, yet unrealized, potential of health IT emerged. In order to consider the various stakeholders that could be impacted by the advances of a robust HIE, research must begin to field and analyze their opinions in order to consider this feedback into design, development, and integration. Conversations with health care professionals, practitioners, researchers, and social workers utilize each groups' unique knowledge and provide the opportunity to move forward proactively rather than reactively. Many scholars consider these collaborative conversations as integral to achieving robust HIE (Vest & Gamm, 2010; Poulymenopoulou et al., 2013; Nyguyen et al., 2014; Salas-Vega et al., 2015; Adler-Milstein et al., 2017; Aziz, 2017; Haluza & Jungwirth, 2018).

Thus, in-depth, semi-structured interviews will be conducted across the diverse fields. Qualitative interviews have been widely cited as imperative moving forward with health IT advances (Mays & Pope, 2000), and have grown more common and increasingly accepted in healthcare research (2000; Marie & Higginbottom, 2004; Gill, Stewart, Treasure, & Chadwick; Kallio, Pietila, Johnson, & Kangasniemi, 2016). Additionally, the rapid rate of technological advancement within the field has arguably rendered previous research obsolete, as many of the aforementioned barriers may be ameliorated by technology. Unfortunately, technical barriers often mask a deeper root issue. Discussions with the participants will provide a better sense of what the sentiment surrounding S-HIE—the barriers, the potential, the need, the growing conversation—is today, in actual practice.

3.2 SAMPLING

The researcher's exposure and current exposure in the healthcare field enabled utilization of a convenience sample to amass a participant pool. A convenience sample is readily available and easy to find (Marie & Higginbottom, 2004). Through projects within a health care organization, lectures on topics related to the research questions, and area-related networking, potential participants within the clinician, public health, health IT, and social work groups have been identified over the course of a year prior to the research via purposive sampling (2004). Participants were given the option to recommend other individuals that may be interested in or pertinent to the study, thus snowball sampling was utilized as well. Marie & Higginbottom (2004) discuss these methods as an iterative process of sampling. The number of participants shifted as the study evolved. Initially, the study was to include one participant from each group, but participants

suggested others and an additional participant was added to each group. Scheduling conflicts prevented the second social worker from participating. Though the sample was kept small, additional participants provided further insight and more data. These non-probability methods of sampling allow for insight into what is happening, and while some scholars argue that a smaller sample size hinders generalizability (2004; Julien, 2008), it provides depth and understanding at level unattainable with many quantitative methods. Following IRB approval, #18-9056, participants were informed of the study and asked if they are willing to participate. As this study involved interviewing human participants, the greatest care was taken to ensure that all participants feel at ease with the interview and understand their option to withdraw at any time. Marie & Higginbottom (2004) suggest that a lack of transparency in qualitative research, sampling techniques in particular, leads to overall criticism. In an effort to be transparent, the researcher acknowledges a range in personal relationships amongst the participants. Three participants are long-standing friends of the researcher. Their professional experience, years in the field, and exposure to health IT qualified them for the study. Certain familiarity promoted active involvement by the participant and ease of rapport while maintaining focus on the research mission.

3.3 DATA COLLECTION

Semi-structured interviews were chosen because they provide some structure while allowing the interview to elicit a response or direction that may not have been foreseen by the researcher. Beyond this versatility, they encourage reciprocity and rapport between the researcher and participant, creating a dynamic that a more rigid approach would impede (Gill et al., 2008; Kallio et al., 2016) A systematic review of the literature

regarding the barriers to HIE (Almoaber & Amyot, 2017) found that semi-structured interviews were the most used source of data collection. Other methods were workshops (Rigby et al., 2011), town hall meetings (Nguyen et al., 2014), Delphi surveys (Haluza & Jungwirth, 2018). Aspects of these studies as well as the semi-structured interviews done by Laforge et al. (2018) and Nguyen et al. (2014) will be considered in preparation for this research. This study will be done at an individual level, as certain opinions or topics may be of sensitive nature. This will provide insight for further research to be done in group environments in the future. Reviews of the literature and exposure to issues regarding health IT, HIE, and holistic care have highlighted certain tensions between groups, thus research must be done in a way that acknowledges that. Gill et al. (2008) emphasize that semi-structured interviews with individuals allow researchers to cultivate a deeper understanding. In particular regards to healthcare, they are useful in providing some guidance for the participants that may be unfamiliar with certain topics or questions (2008).

Kallio et al. (2016) discuss the influence of the quality of the interview guide on a study's results, suggesting that rigorous development of the guide ensures objectivity and trustworthiness of the results. Given that the findings of qualitative studies have come under scrutiny in the healthcare field (Mays & Pope, 2000), the researcher followed Kallio et al.'s (2016) framework for semi-structured interview prerequisites.

An extensive literature review and immersion in the research area was used to formulate the questions for the interview. Kallio et al. (2016) stress the importance of having a grasp on the topic area in order to conduct an effective interview. Further, given the research question involves fragmented areas, consulting experts in the disparate fields

will produce empirical knowledge to complement scholarly background. Accessing area-specific knowledge may also reveal information that had not been previously considered by the researcher, encouraging the researcher to seek to acquire knowledge rather than give advice or personal opinions.

The quality of the data and research depends on the quality of the interview guide, thus a great deal of care was put forth in its creation. The study aims to encourage proactive and forward thinking, and its exploratory nature lends itself to a certain degree of flexibility and open-mindedness in the interview process. Mindful consideration during the preparation stages will lead to more trustworthy and quality data and results.

Each interviewee will have the same set of questions as the intent is to get a general sense of various stakeholders' opinions on the same topics. This approach will hopefully encourage a deviation from the silos that the conversation surrounding HIE often creates and instead create more collaborative environment in which to have the discussion. The interviews were done in person and recorded. The interview questions will attempt to glean insight into what data and information should be stored, who should be responsible for input, where it should be housed, who should have access to it. Further questions regarding aforementioned barriers, security and privacy concerns, and holistic approaches to healthcare will also be presented.

3.4 DATA ANALYSIS

This qualitative study required extensive analysis of the open-ended responses. Content analysis primarily focused on the in-depth synthesis of the different groups, finding trends and disparities with their responses. Responses from each group will be compared within the group, between other groups, and eventually against the literature, highlighting

where groups intersect, diverge, and deviate from the literature. This will allow for a big picture sense of HIE and how to best move forward in a collaborative way.

Ultimately, the current literature, current news, and general sentiment surrounding HIE and health IT seem to lack cohesion and basic understanding. This study aims to analyze the viewpoints of the stakeholders, address the gaps in the conversation, and provide a framework for further research and efforts moving forward.

RESULTS

4.1 OVERVIEW

A total of seven professionals participated in the study. Two health informaticians, two nurses, two clinicians, and one social worker were interviewed. Following the interviews, the recordings were transcribed by the researcher. Inductive coding analysis was done in stages to allow themes to emerge through thorough examination of each interview and then through comparison. A concept spreadsheet was created following the initial hand-coded content analysis of the printed transcripts.

The participants defined health information, health IT, SDH, and holistic healthcare in their terms. They also explained the current state of health IT and their frustrations with the current EHR and HIE systems. Attitudes regarding holistic healthcare and the potential benefits of seamless HIE were garnered as well.

4.2 DEFINING HEALTH INFORMATION & HEALTH IT

Before addressing the research questions and conceptualizing a robust system for social-HIE, it is imperative to understand how different parties define health information. Inf2 made the critical distinction between data and information, stating that data are pure data elements, the “nuts and bolts,” that evolve into information when they are put in context and given meaning.

4.2.1 Health Information

A theme of identifying health information in broad and basic terms emerged, with all participants using one or both terms in their definition. Doc2 emphasized the need to start broadly at this stage of health IT. Five participants extended the definition to be inclusive of anything that affects an individual's health and well-being, including physical, mental, social health and biological and environmental factors. All participants distinguished between traditional healthcare data that is currently captured in an EHR, including vitals, chief complaints, medical history, allergies, measurements, and insurance data and non-traditional elements such as air pollution, FitBit data, communication preferences, and social history.

4.2.2 Health IT

Following a consensus of less traditional and all-encompassing definitions of health information, the participants had a more straightforward opinion regarding health IT. All participants spoke to the information systems used by providers, patients, insurance companies, and public health organizations to communicate and exchange information pertaining to health. Inf2 aptly identified health IT as the systems and infrastructure "utilized, technology and otherwise, to facilitate the use of health information and the sharing of it." Other themes that emerged were the various applications of health IT, including software implementation, data security, database administration. Between these applications and the collection, storing, dissemination and analysis of data with EHRs, health IT is regarded as making the data more meaningful and impactful. The EHR systems discussed were primarily EPIC and Cerner. EHRs, telemedicine, and patient portals were mentioned as examples of health IT. Extending beyond the systems, four

participants included technology that facilitates care, monitors patients and keeps hospitals up and running in their definition.

4.2.3 Health Information Exchange

In defining HIE, all participants included the "sharing of health information" between amongst various parties in some form. Beyond that, the participants had a more difficult time coming up with a succinct definition of what exactly HIE meant. In their definitions, all participants defaulted to an idealistic view of what HIE could be or could achieve. While the clinical professionals limited the exchange to providers, patients and insurance companies, the data informaticists expanded the exchange to all potential stakeholders and stated that HIE enabled the seamless exchange of information improves the ability for all players to make better decisions and provide better care for individual and public health. The "central pool of health information," as defined by inf2 enables the appropriate person to "get the information they need, no matter where they are and no matter where the data is," according to inf1. Doc1, doc2, and inf1 all spoke to the silo factor crippling HIE. Inf1 and nur2 both discussed the protocol and regulations involved when dealing with the sharing of records.

4.2.4 Holistic Care & Social Determinants of Health

Responses regarding holistic care and social determinants of health were more consistent across the participants than expected, given the variation of fields represented. Each participant acknowledged that viewing a patient holistically went beyond traditional approaches to healthcare, with inf1 suggesting that it "takes into account bits and pieces [of information] about people that may not necessarily be reflected in their medical chart." The sentiment that holistic care meant caring for the whole person,

acknowledging the systems of influence on an individual's health as opposed to strictly treating a symptom. Frequent social determinants of health named were mental, physical, social, economic, community, academic, and environmental. Nur2 claims "everything you do, say, eat and breathe is health information," a sentiment shared by three other participants who noted that where one lives and one's access to food and reliable transportation were critical pieces of health information.

The participants were split regarding whether SDH qualified as health information, with the clinical professionals distinguishing them from health information and nur2, soc1, inf1, and inf2 regarding them as health information. Nur1 noted that she "certainly doesn't think of social history and SDH first when [she] thinks of health information," adding that she views them separately but linked. All participants acknowledged the difficulty in quantifying and measuring SDH.

Other minor themes emerged from this question. An unanticipated factor of spirituality was brought up by soc1 and nur2, and cultural beliefs were discussed by two other participants. Soc1 and inf2 brought up the issue of access and equity. Doc2, soc1, and inf2 emphasized the importance of SDH information in order to look at patient from their perspective.

4.3 CURRENT STATE OF HEALTH IT & HIE

Participant responses regarding the current state of health IT and HIE were unexpectedly those of frustrations and unrealized potential. 53 statements or quotes were coded under "frustrations" with the current systems in the concept map. Thematic frustrations will be addressed in further detail below. Another major theme that emerged was the general sentiment that the current reality is not living up to expectations or potential, with many

participants citing the infrastructure being built around billing and insurance as a hindrance. Each participant was adamant about the current EHRs are an improvement to legacy systems. Soc1 suggests the systems have grown "leaps and bounds" in regards to billing patients, but inf1 acknowledges that the EHRs were "designed to be able to bill patients for their visit, and to be able to meet federal guidelines such as Meaningful Use." Doc2 recognizes that technology itself is new, and emphasizes that health IT is even newer. Participants view the current state of health IT as a "beta phase," "try phase," and "learning phase." The rollout of EHRs was deemed "clumsy and inefficient" with the majority of the participants wondering if the rush to automate everything and meet requirements led to poor execution and ineffective implementation. Inf2 and nur2 acknowledged that different systems serve different purposes and different rules are applied to different data sets, making the implementation even more challenging.

4.3.1 Frustrations—Design

Three participants on the clinical side expressed poor frustration regarding the poor design of EHRs. They all commented on the EHRs being mimicked after paper charting, simply making it electronic. According to the clinicians, this is not intuitive nor conducive to workflow. Doc2 stated that providers are essentially "glorified data clerks" due to the design of EHRs, with all four clinicians expressing frustration over the sheer number of clicks it takes to accomplish anything within the system.

They also expressed concerns over the amount of time it takes to interact with the system and the impact on patient interactions, as the time they spend in front of a computer takes away from time spent communicating with the patient and other important parties. The

EHRs also lack an update and alert mechanism, thus providers spend time watching the computer screen or contacting other parties in order to track processes.

Another major theme regarding notes emerged when analyzing the discussions of the current EHR systems. Due to the poor design of the systems, providers often cannot figure out where to input certain information and do not have the time to figure it out. This leads to blank patient notes becoming a catch-all of information that is "cumbersome and time-consuming to get through." Nur1 explained the scenario in which none of the staffed nurses know where to input data, and they have to put it in a blank note, despite knowing that is not the right way to do things. These actions lead to downstream delays in care when other providers must sift through notes in order to try to glean information from rushed notes. From a public health and informaticist standpoint, there are deleterious effects of having important information buried in notes because providers are rushed or do not have anywhere else to put that information. Inf1 stresses that unstructured data is not as useful and is harder to analyze.

4.3.2 Frustrations—Fatigue

A theme of fatigue was found when analyzing the poor usability of the systems. While providers mentioned being forced to put data into notes due to the format of the system, they also mentioned defaulting to notes out of fatigue. Each clinician mentioned that they themselves and their staff have already employed shortcuts and workarounds due to the sheer burden of entry. This inability to use the system effectively and efficiently causes providers to "choose between patient care or figuring out this 'IT thing,'" as nur1 put it. Nur2 discussed that some providers ultimately end up bypassing the system all together because it is one more step in their process. Nur1 also mentioned feeling that data entry is

not her job, a common sentiment amongst the providers as they consider who ought to bear the burden of entry.

All of the clinical participants also spoke to the variability in user ability amongst practitioners and nurses. Though the four participants are all comfortable with technology, two of them being self-proclaimed "computer [people]," they discussed their co-workers being less familiar and therefore less comfortable and confident in using computers. Soc1 and doc2 noted that being uncomfortable with basic computer usage creates additional frustration and more barriers for these individuals who are unable to do their jobs, ultimately leading to general user fatigue and resentment towards health IT.

4.3.3 Frustrations—Silos

A primary concern shared by all participants was the idea that the current state of HIE is one of siloed information. Doc2 responded that the first word that comes to mind when they think about HIE is "silos." The impact of silos on interoperability will be examined further in the considerations section, but these silos also play a role in the day-to-day functionality and utility of the EHRs. All of the participants stated that the information in these silos are heavily guarded by the data stewards and the lack of access to information in a timely, efficient manner leads to delays in care and in some cases unnecessary or redundant care. These delays, which were found to last anywhere from a few minutes to a few weeks, cause frustration amongst providers because they "know the information is available" but they are not able to access it electronically and instead have to print it out or wait for a fax. Annoyance regarding the continued use of faxes at this stage in health IT was a theme found amongst the clinical participants.

Soc1 noted that there was no way for clinicians to access their notes, supporting nur1 and doc2's statements that communication between patient and providers, as well as within a system has vastly improved, but the interoperability with other systems is still lacking. This requires that clinicians and public health professionals must rely on contacting each other directly, often times waiting for days for a response. Nur1 explained that if someone requests information on a Friday night, they can expect to wait until Monday morning for a response. These delays create further frustration amongst professionals as they are seen as avoidable with proper cross-talk between systems.

4.4 HOLISTIC CARE & SOCIAL DETERMINANTS OF HEALTH

Responses regarding SDH and their impact on an individual's overall health and wellness were overwhelmingly consistent and favorable, with all participants citing that research correlates SDH with health outcomes. While all of the participants recognized how influential SDH are on an individual's health, only five participants suggested that they are overlooked. All participants did state that integrating SDH data, such as environmental factors, financial and emotional landscapes, and systemic influences, and pursuing more holistic healthcare would ultimately lead to better care and positive long-term effects. The four clinicians discussed experience in patients of low socio-economic status utilizing emergency services more frequently, with return visits being common amongst them as well.

4.4.1 The Paradigm Shift

Though the importance of SDH and a more holistic approach were thematic in responses, another theme emerged regarding the current system not being set up to provide holistic care. Nur1 mentioned that the way the EHR is set up influences the way providers

structure information in their minds. Inf2 stated that holistic approaches were an "alternative to thinking strictly clinical." Doc2 stressed the need to incorporate the research we have that supports holistic approaches into predictive analytics and early prevention efforts. All participants stated that awareness of SDH were influential at the point of care as well as longitudinally.

Though soc1 suggested that the holistic mindset was less common amongst clinicians, the clinical participants supported the approach while accepting the difficulty in pursuing it. Nur1 and nur2 provided insight into the clinicians reservations in collecting SDH data, discussing that healthcare providers do not want to collect data on a patient that they are incapable of dealing with. Gathering this data and adjusting care and treatment plans are time-consuming for both the patient and providers, because as nur1 explains it is "easier to prescribe or take a pill to treat the symptoms rather than taking a few steps back and examining the systems that got you there." Six of the participants discussed the challenges surrounding addressing SDH, with four participants giving examples of two participants suggest are hindering the shift to more holistic care.

4.4.2 Collecting, Measuring, & Representing SDH

The most frequently discussed barrier to holistic care were the nuances of collecting, measuring, and representing SDH. Six of the participants spoke directly about how difficult and time-consuming it is to get SDH data into the EHR in a way that is useful to all parties. While stressing the importance of SDH data, nur1 explained that the industry has yet to be made aware of just how critical they are because until we figure out a way to quantify the data can we utilize them for research and eventually to improve patient care.

The major themes found during analysis were that SDH are rarely dichotomous and cannot be accounted for with a check box and thus often wind up in notes as unstructured data that is hard to analyze and are susceptible to semantic and interpretation errors. Multiple participants used food insecurity to illustrate that SDH data are not binary. As nur2 exemplified, “what does it mean to be food insecure? Are you hungry sometimes or do you not have food every day?” Further complicating this is that SDH are susceptible to subjective interpretation, as two participants acknowledged. How one person defines something may not be how another defines or interprets something, which could have serious consequences.

The way in which SDH often get buried in notes or have to be discerned from other information available in the EHR was brought up by six participants. This has negative impacts on both patient visits and data analysis. Nur2 explained that when SDH are in the form of paragraphs in notes, it takes too long to sift through to find out if anything in the note is pertinent. Doc1 described having to utilize insurance information in order to try to ascertain environmental triggers relevant to treatment plans. Inf2 noted the added difficulty in doing data analysis on unstructured data versus data gathered in a patient’s chart.

4.5 CONSIDERATIONS & CONCERNS

All participants noted that despite the frustrations amidst the current state of health IT and HIE, that healthcare will continue the trend towards automation and that ultimately technology can support improved patient care and greater public health outcomes. Several themes developed when discussing concerns about moving forward with health IT and considerations to ameliorate them. The themes aligned with the aforementioned

barriers to HIE, privacy and security, technical and organizational, financial, and stakeholder buy-in. Notable emphasis was placed on semantic, access, and literacy gaps, as well as clarifying what data ought to be collected.

4.5.1 Privacy & Security

Six of the participants stated privacy and security as a primary concern regarding the electronic exchange of health information. Doc1 and doc2 brought up liability concerns and the potential for people to access the data and use it in nefarious ways. Nur1 and nur2 acknowledged that there are certain safeguards in place, such as HIPAA, to protect patient health data, but were quick to admit that these laws are often violated in practice. Another theme was patient perception of having extensive data about them available to multiple parties. Nur1 admitted some push-back from patients as it feels a bit "big brother-ish." Inf1 emphasized the "point of having data and sharing it is not stalk patients but to get as much information about a patient's whole life so that we can take better care of them." Five of the participants discussed the importance of patient consent and data disclosures in efforts to alleviate patient concerns.

4.5.2 Technical & Organizational

Unexpectedly, none of the participants readily named who ought to incur the burden of data entry. Two participants felt a trained social worker or data expert would be best suited to do this, while five of the participants advocated for a shared, team approach to data entry. Nur1 explained that "nobody necessarily has the time to add on all the data entry to their job" and doc1 stated that it is more appropriate for certain people to collect information at certain times. The data informaticists also supported this, given that various people are interacting with the patient during the visit and throughout their lives,

and it makes sense that anyone that obtains relevant information ought to enter it in the patient's record. Inf2 further suggested that when relevant information was added to a record, that all affected parties be notified of the update. Only one person considered that providers entering data would decrease the burden on the patient.

Five participants were concerned with data loss and quality. Four clinicians noted the potential for data to be erroneously entered into the system, and three of them discussed the possibility that some patients and providers may never "get" the information because they do not check their e-mail or miss a phone call or voicemail. Inf1 examined the domino effect of making conclusions based on bunk data when we give everyone access to data and allow anyone to input data, "there are obviously huge quality concerns, because you could be a terrible steward of data."

In addition to the aforementioned frustrations with the current design of HIS, each participant communicated the need to redesign the systems in order to achieve interoperability amongst the necessary systems. Inf1 and doc2 suggested that the forced rollout to meet federal guidelines led to EHR systems that were poorly designed. Both informaticists discussed that the "byproduct data" from EHR systems designed with insurance, billing and guidelines in mind should drive need-based interventions and the need for a system that support that. Five participants mentioned the silo effect and the inherent difficulty of getting the vast number of databases and systems to interface consistently and seamlessly. Inf2 discussed the need for public and private sectors to communicate with each other and noted that the current design of systems does not allow that collaboration. Soc1 stated the importance of physicians considering their notes in their treatment but acknowledged the lack of functionality within the system for that to

happen. Inf1 cautioned against building an EHR that was too busy and created information overload and instead suggested having a system that gave the provider the option to view certain information. Three of the clinicians discussed concerns about being inundated with too much information, but two stated they have often learned critical things about a patient when sifting through information.

4.5.3 Financial

The informaticists were the only participants to discuss financial considerations and who was incurring the monetary costs on HIE initiatives. Inf1stated that leadership was willing to "put forth funding if particular information exchange is believed to have a direct and immediate impact on human health." Inf2 acknowledged the differences between public and private sector timelines, freedom for innovation and risk in decision making. Inf2 noted that "the commercialization of healthcare makes it difficult to be on the same page while ensuring we put the patient at the center of healthcare."

4.5.4 Buy-In Amongst Stakeholders

It is the financial expense of the trial period that requires collective buy-in amongst stakeholders. Inf2 stated that the burden was on public health to advocate for HIE to those that control the funding. Four participants emphasized the need to have all stakeholders working in tandem throughout the entire process, with three insisting that it is just as critical to have all parties consulted in the design as it is to have them sharing their data and information. Inf1 stressed the importance of treating IT as an interdisciplinary science in order to create systems that "support rather hinder" clinical workflow. Soc1 and doc1 mentioned that the medical field has become subspecialized, which further exacerbates the silo effect. Four participants focused on the need for

communication between physicians and designers in order to improve the systems with a shared vision. Doc1 said they were "willing to sacrifice personal time for long-term gains of making down the line better," a sentiment shared by all of the other participants. Inf2 noted the tension between long-term and short-term cost effectiveness, adding that when different stakeholders are trying to answer different questions, getting them on the same page aligning resources and political will.

In addition to encouraging design to support clinical practice, the informaticists approached the question from a data exchange standpoint. The system needs to work for the clinicians, but there also needs to be a shift from data hoarding to data sharing. Inf1 introduces FAIR—findable, accessible, interoperable, reusable—data, which enforces data sharing in order to receive funding for research.

4.5.5 Bridging the Gaps

Six of the participants discussed concerns over the potential for health IT widen access gaps. Access gaps were considered in regards to access to resources and access to technology. While acknowledging how health IT could bridge access gaps by providing remote access to healthcare, soc1worried that a whole-scale shift to technology-based healthcare would leave a lot of people behind. Other participants noted that access encompasses access to the technology as well as ability to use it. Doc1, doc2, and soc1 stated that if not properly considered, health IT could worsen the healthcare disparity. Other concerns arose regarding representation in populations and inequalities between medical centers. Given that private industries can improve more rapidly, "the advantaged will become more advantaged, and the disadvantaged are going to be left further behind," notes inf2. All participants recognized that EPIC institutions communicate well with each

other, but inf1stated that this creates a situation where “EPIC institutions and their patients are the haves, everyone else are the have nots.” Three participants noted that while some sort of HIS has been integrated into most medical practices and centers, many rural ones cannot afford a robust system, preventing them from maximizing the utility of HIE and access to the advantages.

Many participants were also concerned about the ramifications of current semantic and literacy gaps. Information may get lost in translation or misinterpreted by various users. Inf1 suggested that health literacy needs to include “what data is being collected, why, how it will be used, and what is the benefit in sharing it.”

4.5.6 What Data to Collect?

As inf2 stated, “we have to agree on what questions we are trying to answer before we can figure out what data we need to ask those questions.” All participants struggled to answer the question concisely, with responses ranging from basic health information, SDH, to obscure data that are not yet collected. As expected, clinicians focused primarily on information necessary at the point of care, while the informaticists focused on data that would have long-term impact. These clinicians were receptive to collecting certain information if downstream relevance for patient and public health was given. Reliable transportation and ability to afford prescribed medications were brought up by the clinicians. Two driving forces were discussed—how much time does one have to collect the information and how relevant is privacy? A theme arose of deferring to the least amount, in addition to the sentiment that sharing must encouraged for everyone’s least amount to have a cumulative impact. Inf2 cautioned against the “trap of collecting data

for data collection's sake," and to instead ensure that the reason and utility for the collecting the data.

Two examples of data that is not collected are ejection fractions and ACE scores, neither of which fall into any aforementioned category of data but research shows that both are vastly influential.

4.6 PATIENT-GENERATED HEALTH DATA

Responses were mixed when asked about PGHD, with many participants viewing it as positive if done properly. Three participants felt that the more agency you give to the patient, the better. It is seen as a great resource for vast amount of data with the ability to give a longitudinal view of the patient rather than just the current a point-in-time snapshot. Concerns included a patient's general compliance and consistent entry, familiarity with and access to technology, and health literacy. Overall, despite the challenges, most of the participants felt it was a good thing and would get patients engaged in their health and raise awareness.

4.7 POTENTIAL, BENEFITS, & THE FUTURE OF HEALTH IT

Three themes developed when analyzing the responses regarding the future of health IT, its potential and benefits: improved patient and provider access to an interoperable system could have vast impact on patient and population health, but there are many factors that the benefits are dependent upon as well as a consensus on the ultimate goal of healthcare. There was a general sentiment that the field will continue to grow, with unlimited and unrealized potential that requires proper design and collaboration to maximize the utility of health IT and HIE. Inf1 and doc2 stated that the current phase is

one of automation and software implementation and that the next phase will have the capacity to have a tangible impact on health outcomes.

4.7.1 Secure Communication

All participants shared the sentiment that the greatest value-added of health IT is the ability to communicate freely while having it be secure. Clinical benefits to this seamless exchange noted were improvements to continuity of care with access to a patient's records, prevention efforts, predictive analytics, reduced lengths of stay, increased patient safety, cost savings to the patient with a reduction of redundant tests and visits, streamlining of care, more accurate diagnoses, remote access and process improvement. Many of the participants called for better communication between professionals of different specialties to help ameliorate the issue of fragmented medicine. Many participants were in favor of a more holistic approach to care, including a collective effort of a team of specialists working with a patient. Most participants suggested that placing data collection and HIE in a larger context and incentivizing collaboration would discourage leveraging data for money and instead encourage people to work together. Nur1 spoke of the importance of these conversations, admitting that they do not consider downstream effects of her notes and charting unless they are explicitly brought to attention. Inf1 stated that the revolutionary potential of health IT is dependent upon conversations with physicians.

4.7.2 Patient Education

An unexpected theme was improving patient education. Multiple participants insisted that informed patients are critical moving forward with health IT, and three discussed the possibility for health IT to improve patient health literacy. Improving health literacy was

said to help the patient understand their health and the impact utilization of their health data has on a greater scale. Other participants stated that patient education would increase patient autonomy and allow them to work alongside their providers to make the best decision for their care. Patient education in tandem with preventative measures was said to result in fewer visits.

Inf1 and inf2 discussed the role financial incentives affect the growth of health IT. Four of the participants acknowledged that there needs to be a combination of efforts from the private and public sectors with come up with an equilibrium for EHRs to be utilized for health outcomes and not solely for billing. A few participants suggested that the government was in the best position to be transparent and secure with the data and could play a role in data stewardship and infrastructure. Three participants called for a vetting procedure to ensure data quality.

4.7.3 The Ultimate Goal

According to doc1, the ultimate goal is to "keep people at home and healthy and being in the hospital is a failure of that." Doc2 poses the question of whether the ultimate goal is for people to be healthier or to extract as much profit as possible. All participants stated that it was essential for all necessary stakeholders to have access to the same information, without paywalls. Doc2 suggested that with a secure systems, there should be no walls to access. The majority of the participants stated that the more you know about an individual, the more accurately you can treat them.

Inf2 stresses that a robust HIE can gather more information that answers more questions and thus meets the needs of multiple players. Multiple participants call for a system redesign that allows the patient to be at the center. Inf1 suggests a design that would give

providers the option of viewing certain information without thrusting it in their face. All of the clinicians stated that a well-designed system would enable them to focus on interacting with the patient during a visit rather than a computer and would help improve the patient-provider relationship.

Soc1 brought up the critical point that "as long as there is disparate access to the underserved, there is a cap to how revolutionary health IT can be." Three additional participants stressed the importance of ensuring universal and equitable access to health IT in order for it to maximize its potential.

DISCUSSION

5.1 COLLABORATIVE EFFORTS

The findings of this study aligned with those of previous research. This study sought to accomplish the frequently discussed collaboration conversation amongst various stakeholders involved in health IT. While the results displayed an anticipated consensus that these conversations are imperative moving forward, given previous research suggesting that conflicting interests drove the stakeholders apart, all participants were unexpectedly willing to engage in these cooperative efforts. The participants were not only willing to sacrifice personal time, they acknowledged the necessity of interdisciplinary teams and many expressed frustration that they were not asked to partake in them. This suggests that the literature does not align with actual sentiment of healthcare professionals and that they need to be included in the process.

5.2 HOLISTIC CARE

The results also indicate an openness to holistic approaches healthcare and integration of SDH. All of the participants were receptive towards S-HIE and its long-term benefits, though many were uncertain about how to move forward with it. Further discussion is warranted to ensure all parties understand the basis if holistic care and benefits of tackling upstream, systemic issues.

5.3 BARRIERS TO IMPLEMENTATION

The results regarding the barriers, frustrations, and considerations for HIE were consistent with the findings Almoaber & Amyot (2017) and Edwards et al. (2010). Privacy and security, financial, stakeholder participation, and technical and organizational were the main categories of barriers. Disparate access and a lack of consensus regarding what data to collect were found to be additional considerations in moving forward. While many frustrations and barriers were discussed, the general sentiment was one of positivity and enthusiasm for the future of health IT. All participants advocated for a more patient-centered healthcare and many expressed that health IT had the potential to facilitate this shift. Though patients were beyond the scope of this study, they must be a part of this conversation going forward and included in further research. This inclusion will ameliorate concerns of creating a system without user input from all potential users, as happened during the initial EHR rollouts.

5.4 PGHD

The participants were mixed on the topics of what data to collect and the role of PGHD ought to be within healthcare. Given the necessity of knowing what data systems are collecting before they can be collected and analyzed, further research must be done in order to determine which parties need what data and why. Additionally, the IoT grows in prominence, PGHD must be discussed before the data becomes susceptible to the same fate as the byproduct data of legacy EHR systems, and the industry finds itself with all of the data without knowing what to do with it or how to do it.

5.5 INFRASTRUCTURE

Many participants felt that robust HIE and interoperable HIS would require government-supported infrastructure. Tensions between the private and public sector were mentioned, but further research could assess the role of both sectors moving forward.

5.6 LIMITATIONS

The limitations of this study are inherent to qualitative methods and the subjective, anecdotal nature of the responses. Though in may be inappropriate to generalize the results, they can be used as a foundational basis and incentive for future research.

CONCLUSION

This study aimed to include various stakeholders in health IT and HIE and answer the questions: what data is to be recorded, what data is to be shared, with whom is the data to be shared, who is to have access to the data, who gets to decide all of this? In order to answer these questions, it is necessary to ascertain the present-day attitudes of the stakeholders concerning existing and ideal systems. Though many of the barriers discussed in this study were consistent with those from previous research, this study found that health professional are optimistic about the potential impact of health IT if certain adjustments are made and staunch efforts taken to ensure interdisciplinary teams were involved in the process.

This study only starts the conversation, but it highlights that the conversation is one that must continue and must include all stakeholders and patients from all walks of life. Additionally, a focus group study with these individuals is recommended

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APPENDIX

INTERVIEW GUIDE

Question #1. How would you define health information?

Question #2. How would you define health IT?

- What are your feelings about health IT?
- What are your biggest frustrations with health IT?
- Where do you think health IT has the potential to revolutionize healthcare, if at all?

Question #3. What does health information exchange mean to you?

- How would you describe the current state of health information exchange?
- What information should be collected?
- Who should collect it?
- Are you willing to increase the burden of your staff to include certain information?
- How do you feel about patients entering data via remote applications (patient-generated health data)
- What concerns you do you have about data being exchanged?
- In your opinion, what are the biggest barriers to seamless health information exchange?
  - The biggest challenges?
  - The biggest opportunities?
- Is there value to health information exchange?
  - What costs are you willing to incur to ensure seamless health information exchange?
  - Do you think maximizing utility of certain health information would affect your day-to-day?

Question #4. What does holistic healthcare mean to you?

- How do you feel about holistic approaches to healthcare?
- To what extent do you feel social determinants of health play a role in a person's overall health and wellness?
  - How important is it that you have social, mental, and environmental information available to you at the point of care?
- Would you consider benefits to integrating homeopathic approaches to your care/routine?

- How long have you been working in the field?
- Throughout the day, during a shift (which is how long…), how much time do you spend working within an information system?